

**Title:** Why patients decline genomic sequencing studies: Experiences from the CSER consortium

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**Kaiser Permanente, NEXTGEN Non-Responder Survey**

1) Please tell me your reason or reasons for not choosing to participate in this study.

\*Interviewer selects choice that is closest to the respondent's answer. Interviewer reads back that response to confirm that the respondent agrees. The interviewer then prompts the respondent, "Is there another reason?" until no more reasons are suggested by the respondent.

- a. The study did not pertain to me.
  - b. Not interested in participating.
  - c. I did not understand the study.
  - d. Lack of time.
  - e. Previous bad experience with research.
  - f. Concern about losing health insurance/increase in health insurance cost
  - g. Concern about other discrimination that would result from being identified
  - h. Recommendation from my doctor to not participate
  - i. Recommendation from family member to not participate
  - j. Recommendation from friend(s) to not participate
  - k. Afraid of the risk for being a carrier or for having an affected child
  - l. Prefer not to know about risk for any condition
  - m. Because the results of the test would not make a difference in deciding whether or not to have a child
  - n. Against my religious beliefs
  - o. Against my view that people should attempt to change their destiny
  - p. Technology is underdeveloped to be of use to me/still too much uncertainty
  - q. Other (please describe)
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2) Do you currently have any children?                      No        Yes

3) Are there any genetic conditions in your family?    No            Yes            Don't know

a. If yes, what is/are the condition(s)?

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4) Do you know a family of a child with a genetic condition?    No            Yes

a. If yes, what did you think was the overall impact on the family?

Strong negative impact	Slight negative impact	No impact	Slight positive impact	Strong positive impact
<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

5) Are you of Hispanic/Latino/Chicano descent?                      No        Yes    Don't know

6) What is your race? (check all that apply)

- a. White Black or African American
- b. American Indian or Alaskan Native
- c. Asian
- d. Native Hawaiian or Other Pacific Islander
- e. Other \_\_\_\_\_
- f. No response/Don't Know

7) What is your highest level of education –

- a. Haven't graduated high school
- b. High school graduate/GED
- c. Some college/Associates Degree
- d. Bachelors Degree
- e. Graduate Degree (Masters, JD, MD, PhD, etc)
- f. No response/Don't Know

8) Are you currently...

- a. Employed for wages
- b. Self-employed
- c. Unemployed and looking for work
- d. Unemployed but not currently looking for work
- e. A homemaker
- f. A student
- g. Retired
- h. Unable to work

- i. No response/Don't Know
- 9) What is your marital status?
- a. Now married
  - b. Widowed
  - c. Divorced
  - d. Separated
  - e. Never married
  - f. No response/Don't Know
- 10) What is your total household income?
- a. Less than \$20,000
  - b. \$20,000 to \$29,999
  - c. \$30,000 to \$39,999
  - d. \$40,000 to \$59,999
  - e. \$60,000 to \$79,999
  - f. \$80,000 to \$99,999
  - g. \$100,000 to \$149,999
  - h. \$150,000 or more
  - i. No response/Don't Know

## University of Washington NEXT Medicine Study – Documentation of Rationale for Decline

After hearing about the study, did the patient agree to be considered for further screening?

No Yes

If No, what was the reason the patient declined to be screened further?

- ☐ Too much of a time commitment
  - ☐ Not enough incentive to participate
  - ☐ Not interested in research
  - ☐ Concerns about privacy
  - ☐ Too much blood drawn
  - ☐ Patient declined to provide a reason
  - ☐ Other
- (check all that apply)

If Other, what was the reason provided?